

AMENDED IN SENATE APRIL 29, 2003

AMENDED IN SENATE APRIL 9, 2003

SENATE BILL

No. 231

Introduced by Senator Murray

February 14, 2003

An act to add Section 124982 to the Health and Safety Code, relating to hereditary disorders.

LEGISLATIVE COUNSEL'S DIGEST

SB 231, as amended, Murray. Hereditary disorders: ~~Genetic Services~~ *Newborn Screening* Advisory Committee.

The Hereditary Disorders Act requires, among other things, the Director of Health Services to establish any regulations and standards for hereditary disorders programs that the director deems necessary to promote and protect the public health and safety.

This bill would require the director to appoint a ~~Genetic Services~~ *Newborn Screening* Advisory Committee with members who meet specified qualifications.

This bill would require the committee to meet at least annually to review ~~genetic services~~ *newborn screening* programs and to report annually to the Legislature and the Governor on or before October 30 on specified topics.

This bill would authorize the committee to apply for and receive federal and private funding to fund its activities. This bill would provide that the committee shall operate exclusively from these funds, and shall only operate to the extent these funds are available.

Vote: majority. Appropriation: no. Fiscal committee: yes. State-mandated local program: no.

The people of the State of California do enact as follows:

SECTION 1. Section 124982 is added to the Health and Safety Code, to read:

124982. (a) The director shall appoint a ~~Genetic Services~~ *Newborn Screening* Advisory Committee and establish rotating terms of service for the committee members.

(b) The committee shall consist of one or more individuals affected by a genetic disorder or parents of individuals affected by a genetic disorder; advocates for women and childbirth issues; health care providers specializing in clinical genetics, pediatrics, obstetrics, molecular biology, cytogenetics, and biochemical genetics; representatives of hospital administration, the insurance industry, the biotechnology industry, and genetic counseling; and professional organizations representing physicians and registered ~~nursing~~ *nurses*.

(c) The committee shall meet at least annually and shall review ~~genetic services~~ *newborn screening* programs conducted under the Hereditary Disorders Act , and report to the Legislature and the Governor annually on or before October 30 with respect to all of the following:

(1) The availability and utilization of ~~genetic services~~ *newborn screening*.

(2) The quality of services provided.

(3) The cost and funding of services.

(4) The need to discontinue or add additional services or improve the quality, quantity, distribution of services, or provider reimbursement.

(d) Committee staff shall include at least one full-time position.

(e) The committee may apply for and accept federal funds for the purpose of funding the activities of the committee. In addition, the committee may accept gifts and donations from any source, including individuals, philanthropic foundations or organizations, corporations, or corporate endowments. The acceptance and use of federal funds, gifts, or donations may not entail any commitment or pledge of state funds, nor obligate the department to continue the programs or activities for which the federal funds are made available. The committee shall operate exclusively from

- 1 private and federal funding and shall only operate to the extent
- 2 these funds are available.

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